



Mortality Data Review

Indiana Division of Disability and Rehabilitative Services
Bureau of Quality Improvement Services

Date of Death: January 1, 2015—December 31, 2015

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Purpose

The Division of Disability and Rehabilitative Services (DDRS) Bureau of Quality Improvement Services (BQIS) works with providers and organizations that administer services to individuals with intellectual and developmental disabilities. BQIS reviews the deaths of all individuals receiving services through the Bureau of Developmental Disabilities Services (BDDS). The purpose of the mortality review is to identify trends, develop recommendations, and bring about improvement in both provider-specific and system-wide service delivery. The information presented in this report is reflective of the data collected during the mortality review process.

The information contained within this report is based on deaths during the timeframe January 1 through December 31, 2015 as reported to the Bureau of Developmental Disabilities Services through February 15, 2016 via a death-of-person incident report. Data compiled by Advocare, LLC.

Please submit questions or comments to the Bureau of Quality Improvement Services at BQISHelp@FSSA.IN.gov.

Individual Population

Waiver and Non-waiver Programs

The Bureau of Developmental Disabilities Services administers programs to approximately 26,000 individuals.

Waiver Funding Sources	
Individual Population as of December 31, 2015	Individuals
Family Supports Waiver	11,634
Community Integration & Habilitation Waiver	8,690
Total	20,324

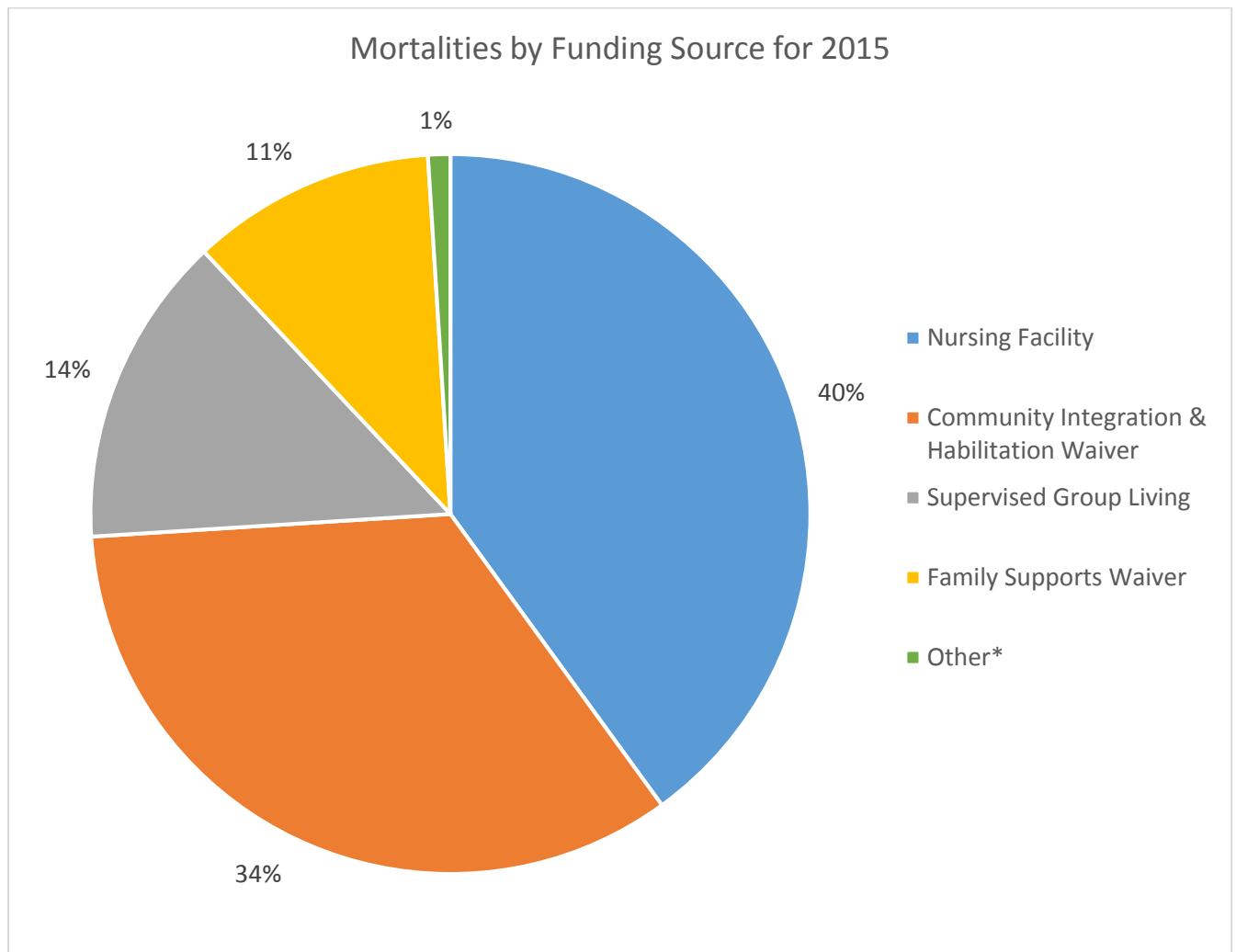
Data Source: State of Indiana INsite database

Non-waiver Funding Sources	
Individual Population as of February 23, 2016	Individuals
Supervised Group Living	3,263
Nursing Facility	1,596
Caregiver Supports	1,177
State-operated Care Facility	63
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	51
Total	6,150

Data Source: State of Indiana DART database

Mortalities by Funding Source for 2015

January 1 through December 31, 2015



*The category "Other" is comprised of Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities and State-operated Care Facility.

Total Mortalities = 400 | Data Source: State of Indiana DART database

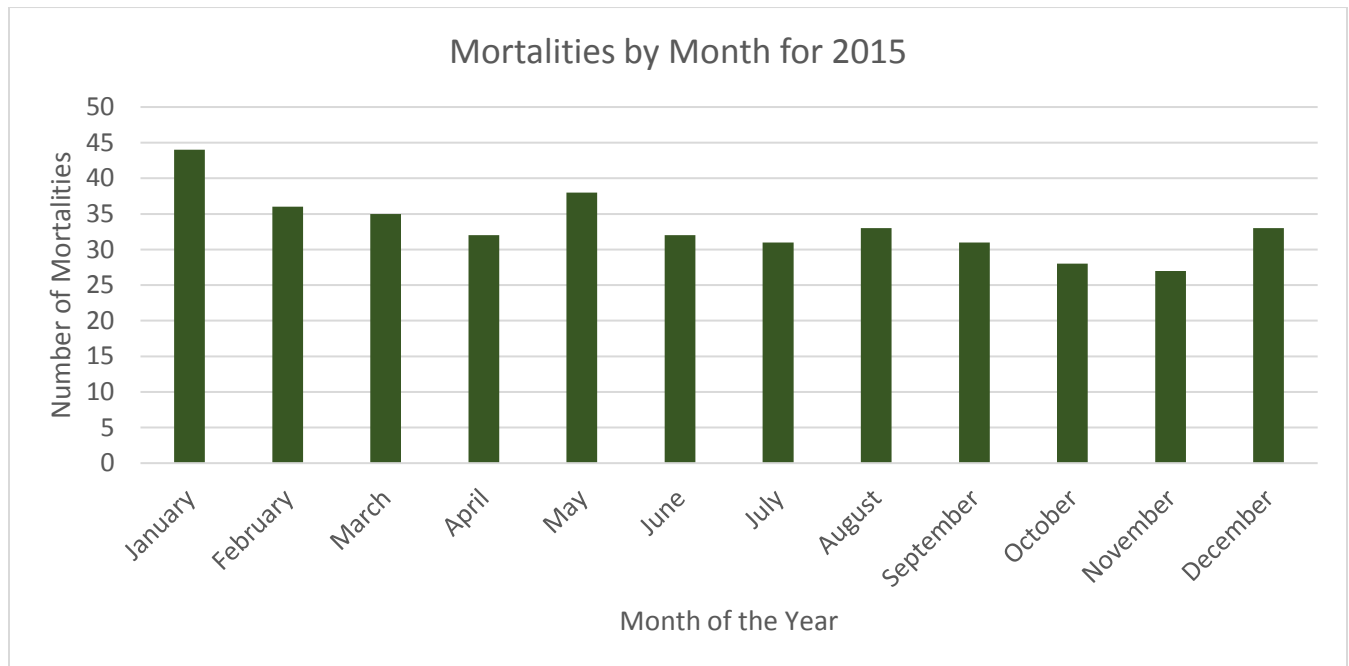
Mortalities by Funding Source for 2015	Count	Percent
Nursing Facility	159	40%
Community Integration & Habilitation Waiver	137	34%
Supervised Group Living	58	14%
Family Supports Waiver	44	11%
Other*	2	1%

Total Mortalities = 400 | Data Source: State of Indiana DART database

Mortalities by Month for 2015

January 1 through December 31, 2015

The noted high mortality rate for January 2015 is consistent with the January 2014 mortality rates for both the national and Indiana general populations. (Note: Data reports for general populations are not yet available for 2015.)



Total Mortalities = 400 | Data Source: State of Indiana DART database

Mortalities by Month for 2015			
Month	Count	Month	Count
January	44	July	31
February	36	August	33
March	35	September	31
April	32	October	28
May	38	November	27
June	32	December	33
		Total	400

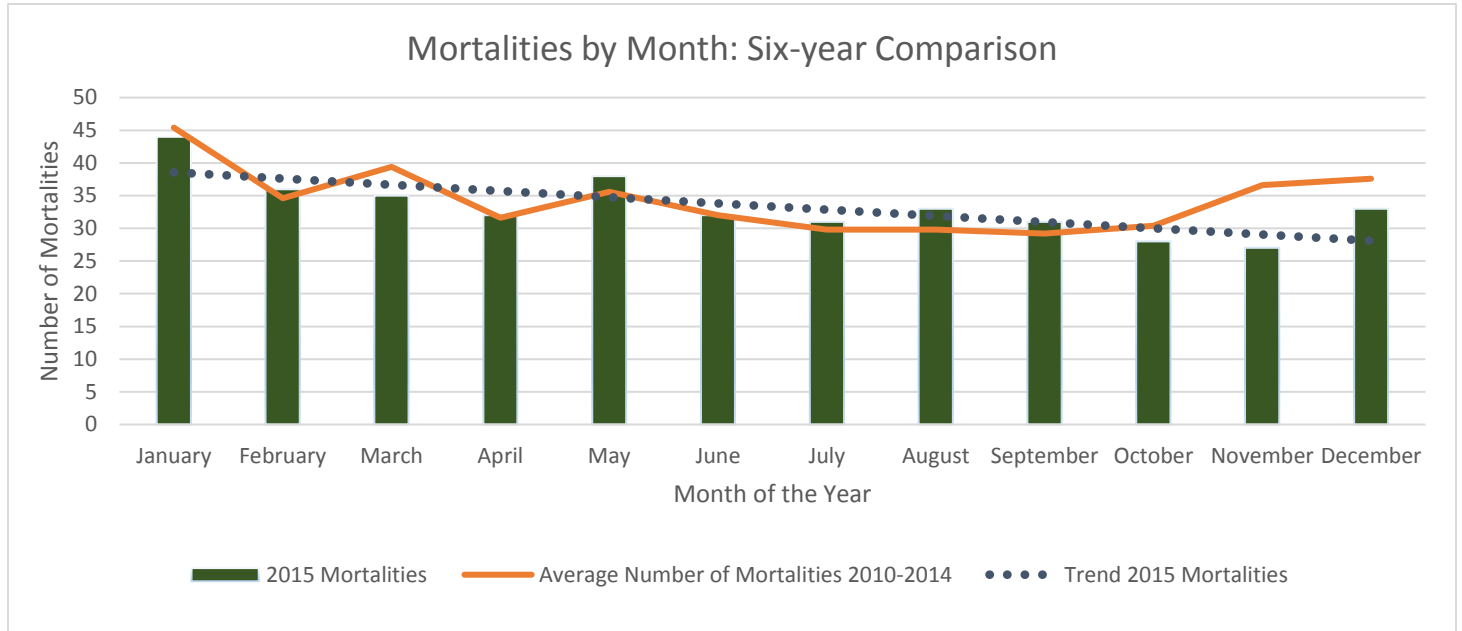
Total Mortalities = 400 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on April 4, 2016 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Month: Six-year Comparison

January 1 through December 31, 2015

The mortality data for 2015 for individuals receiving services through the Bureau of Developmental Disabilities Services shows an overall decreasing trend for the year compared to the general populations at the national and Indiana levels of mortalities in 2014, which were flat for the year. (Note: Data reports for general populations are not yet available for 2015.)



Total Mortalities = 400 | Data Source: State of Indiana DART database

Mortalities by Month: Six-year Comparison						
Month	2010	2011	2012	2013	2014	2015
January	49	43	33	49	53	44
February	41	34	30	31	37	36
March	37	44	37	37	42	35
April	34	31	29	28	36	32
May	31	36	44	43	24	38
June	31	26	32	39	32	32
July	27	30	37	25	30	31
August	28	27	37	24	33	33
September	28	28	28	32	30	31
October	37	26	34	29	26	28
November	37	43	33	33	37	27
December	29	41	30	38	50	33
Total	409	409	404	408	430	400

Total Mortalities = 400 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on April 4, 2016 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Gender and Funding Source for 2015

January 1 through December 31, 2015

During 2010-2014, females and males each comprised approximately 50% of the mortalities in both the national and Indiana general populations. In 2015, the percentages of mortalities of females and males in the population of individuals served by the Bureau of Developmental Disabilities Services were similar to the percentages of mortalities of females and males in national and Indiana general population data. (Note: Data reports for general populations are not yet available for 2015.)

Mortalities by Gender and Funding Source for 2015			
Funding Source	Male	Female	Total
Nursing Facility	88	71	159
Community Integration & Habilitation Waiver	72	65	137
Supervised Group Living	32	26	58
Family Supports Waiver	23	21	44
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	1	0	1
State-operated Care Facility	1	0	1
Total	217	183	400

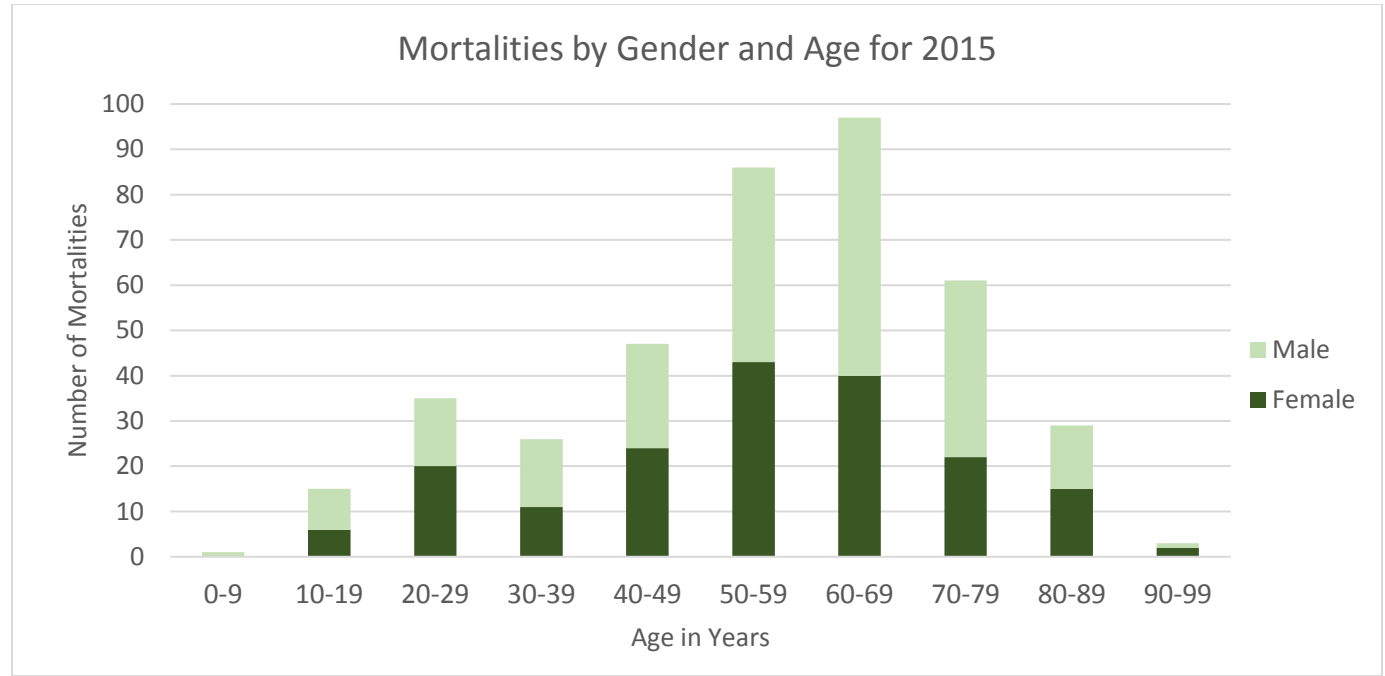
Total Mortalities = 400 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on April 4, 2016 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Gender and Age for 2015

January 1 through December 31, 2015

In 2015, mortalities by gender and age of the individuals in the population served by the Bureau of Developmental Disabilities Services were similar to national and Indiana general population trends in 2014 for age groups 10-19, 60-69, 80-89, and 90-99. (Note: Data reports for general populations are not yet available for 2015.)



Total Mortalities = 400 | Data Source: State of Indiana DART database

Mortalities by Gender and Age for 2015			
Age in Years	Male	Female	Total
0-9	1	0	1
10-19	9	6	15
20-29	15	20	35
30-39	15	11	26
40-49	23	24	47
50-59	43	43	86
60-69	57	40	97
70-79	39	22	61
80-89	14	15	29
90-99	1	2	3
Total	217	183	400

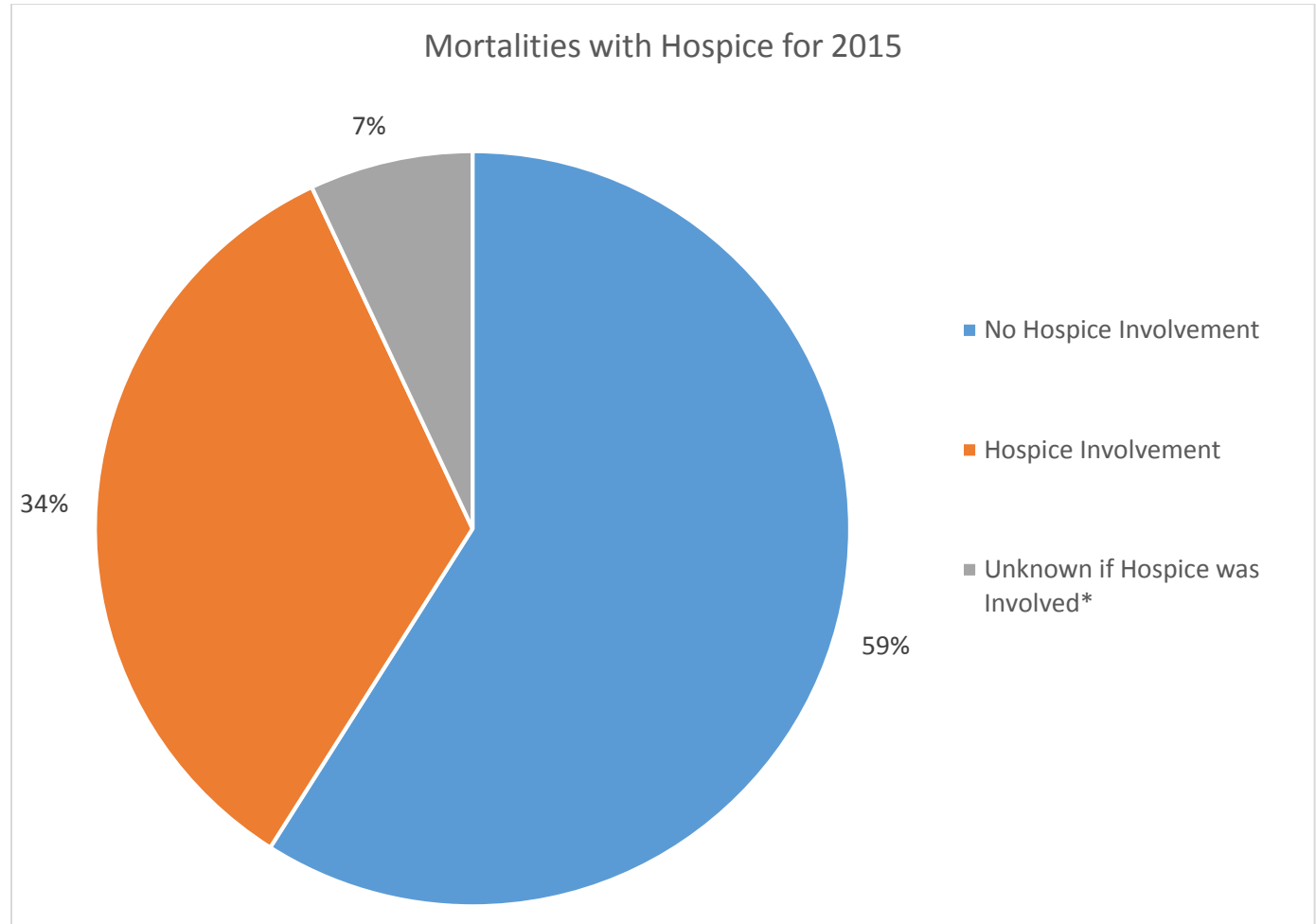
Total Mortalities = 400 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on April 4, 2016 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities with Hospice for 2015

January 1 through December 31, 2015

Hospice care is a comprehensive set of services described in Section 1861(dd)(1) of the Social Security Act, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members as described in a specific patient plan of care.



*Hospice status could not be determined from available documentation.

Total Mortalities = 400 | Data Source: Provider documents submitted during the mortality review process

Mortalities with Hospice for 2015	Count	Percent
No Hospice Involvement	236	59%
Hospice Involvement	135	34%
Unknown if Hospice was Involved*	29	7%

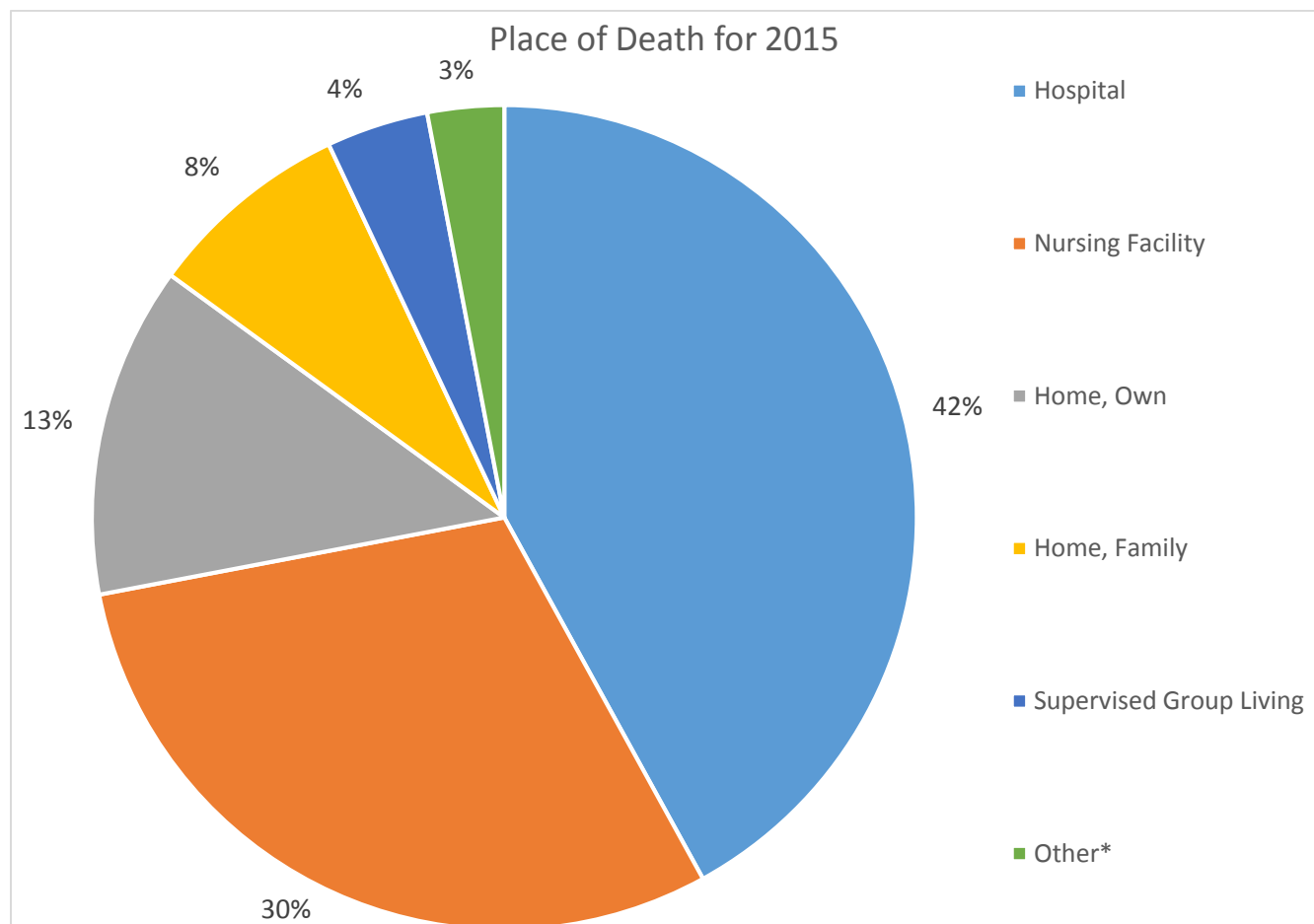
Total Mortalities = 400 | Data Source: Provider documents submitted during the mortality review process

Reference: Accessed on April 4, 2016 at <http://www.cms.gov/Medicare/Medicare-fee-for-service-payment/hospice/index.html>

Place of Death for 2015

January 1 through December 31, 2015

Of the 2015 mortalities for individuals served by the Bureau of Developmental Disabilities Services (BDDS), the 42 percent of deaths in a hospital setting is comparable to 36 percent in the Indiana general population and 37 percent in the national general population. Alternatively, the 30 percent of mortalities in a nursing facility of individuals serviced by BDDS is higher than the 26 percent in the Indiana general population and 20 percent in the national general population. Finally, the 21 percent of mortalities at home for individuals receiving services from BDDS is lower than 29 percent in the Indiana general population and 29 percent in the national general population. (Note: Based on 2014 Indiana and national general population data. Data reports for general populations are not yet available for 2015.)



*Other is comprised of Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities, State-operated Care Facility, hospice, and community settings.

Total Mortalities = 400 | Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process

Place of Death for 2015		
Place	Count	Percent
Hospital	166	42%
Nursing Facility	120	30%
Home, Own	54	13%
Home, Family	31	8%
Supervised Group Living	15	4%
Other*	14	3%

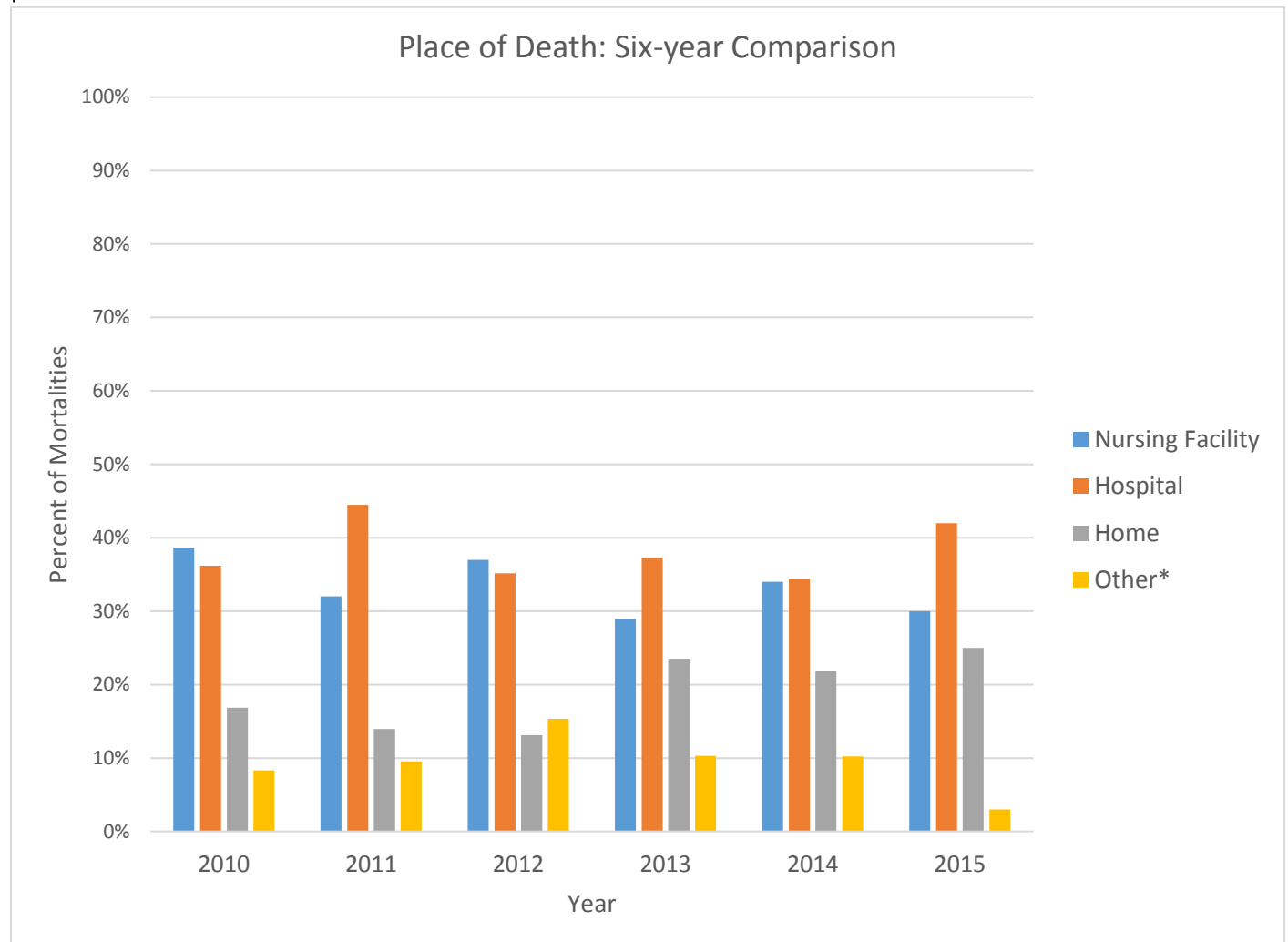
Total Mortalities = 400 | Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999- 2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on April 4, 2016 at <http://wonder.cdc.gov/ucd-icd10.html>

Place of Death: Six-year Comparison

January 1, 2010 through December 31, 2015

Over a six-year time frame from 2010 to 2015, hospitals and nursing facilities were the most frequent places of death.



“Home” includes own and family homes and Supervised Group Living. *“Other” includes Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities, community, hospice, ambulance and unknown locations.

Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process

Place of Death: Six-year Comparison						
Place	2010	2011	2012	2013	2014	2015
Nursing Facility	39%	32%	37%	29%	34%	30%
Hospital	36%	44%	35%	37%	34%	42%
Home	17%	14%	13%	24%	22%	25%
Other*	8%	10%	15%	10%	10%	3%

Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process

Top Five Primary Causes of Death for 2015

January 1 through December 31, 2015

Each specific cause of death as reported by the Indiana State Department of Health is grouped under a major category of death as defined by the International Statistical Classification of Diseases and Related Health Problems-10th Revision. (Note: Based on 2014 Indiana general population data. Data on general populations is not yet available for 2015.)

Top Five Primary Causes of Death for 2015				
Primary Cause of Death for 2015	Average Age	Number of Deaths	Percent of Deaths	Percent of Deaths in Indiana General Population (2014)
Respiratory System	55.2	121	30%	11%
Circulatory System	58.9	57	14%	30%
Cancer	60.4	38	10%	23%
Nervous System	44.6	29	7%	7%
Infections	49.7	18	5%	3%
Total	53.8	263	66%	72%

Total Mortalities = 400 | Data Source: Indiana State Department of Health

Top Five Primary Causes of Death for 2010-2015												
Primary Cause of Death for 2010--2015	2010		2011		2012		2013		2014		2015	
	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%
Respiratory System	71	17%	85	21%	77	19%	86	21%	130	30%	121	30%
Circulatory System	79	19%	77	19%	100	25%	81	20%	107	25%	57	14%
Cancer	51	12%	35	9%	31	8%	36	9%	29	7%	38	10%
Nervous System	18	4%	27	7%	25	6%	29	7%	27	6%	29	7%
Infections	25	6%	30	7%	30	7%	40	10%	22	5%	18	5%
Total	244	58%	254	63%	263	65%	272	67%	315	73%	263	66%

Total Mortalities = 400 | Data Source: Indiana State Department of Health

Reference: International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization. Retrieved April 4, 2016 from <http://apps.who.int/classifications/icd10/browse/2015/en>

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on April 4, 2016 at <http://wonder.cdc.gov/ucd-icd10.html>

Top Three Primary Causes of Death: Decade of Life

January 1 through December 31, 2015

Except for the age groups 0-9 and 90-99, respiratory system conditions are reported as the first primary cause of death in all age groups.

Top Three Primary Causes of Death: Decade of Life			
Age	Cause of Death	Number of Mortalities	Percent of Deaths for Decade of Life
0-9	Circulatory System	1	100%
10-19	Respiratory System	4	27%
	Cardiopulmonary System	3	20%
	Gastrointestinal/Digestive System	2	13%
	Nervous System	2	13%
20-29	Respiratory System	11	31%
	Circulatory System	6	17%
	Nervous System	6	17%
30-39	Respiratory System	9	35%
	Circulatory System	5	19%
	Nervous System	4	15%
40-49	Respiratory System	14	30%
	Cardiopulmonary System	9	19%
	Nervous System	5	11%
50-59	Respiratory System	29	34%
	Cardiopulmonary System	14	16%
	Cancer	9	10%
60-69	Respiratory System	28	29%
	Circulatory System	16	16%
	Cancer	10	10%
70-79	Respiratory System	17	28%
	Circulatory System	10	16%
	Cancer	10	16%
	Cardiopulmonary System	10	16%
80-89	Respiratory System	8	28%
	Circulatory System	5	17%
	Cardiopulmonary System	4	14%
90-99	Circulatory System	2	67%
	Respiratory System	1	33%

Total Mortalities = 400 | Data Source: Indiana State Department of Health

Glossary: Category of Death

Category	Definition	Examples
Abnormal Findings Not Classified	Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified	Abnormal findings on blood, urinary, tissues, or diagnostic imaging without diagnosis
Before/After Childbirth Conditions	Conditions originating in the perinatal period (before and after childbirth)	Disorders related to length of gestation and fetal growth, birth trauma, infections specific to the perinatal period
Blood/Immune Diseases	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	Anemias, blood clots, hemorrhaging, immune disorders
Cancers (Neoplasms)	Diseases in which abnormal cells divide uncontrollably and destroy body tissue.	Prostate cancer, breast cancer, lung cancer, colon cancer, leukemia, lymphoma
Cardiopulmonary Diseases	Diseases of both the cardiovascular and respiratory systems	Cardiopulmonary arrest, cardiopulmonary disease
Circulatory Diseases	Diseases of the circulatory system	Hypertension, heart disease, heart failure, stroke, hemorrhage, atherosclerosis, arteriosclerosis, rheumatic fever
Congenital Conditions	Conditions existing before or at birth, e.g., congenital malformations, deformations, and chromosomal abnormalities	Spina bifida, congenital heart, Down's syndrome, congenital nervous system conditions, congenital respiratory conditions
Ear Diseases	Diseases of the ear and mastoid process	Ear infections, hearing loss
External Causes	External causes of death	Vehicle accidents, suicide, falls, self-injurious, poisoning, assault, complications of medical surgical care
Eye Diseases	Diseases of the eye and adnexa (accessory structures of eye)	Conjunctivitis, blindness, glaucoma, cataracts

Glossary: Category of Death--continued

Category	Definition	Examples
Gastrointestinal/Digestive System Diseases	Diseases of the digestive system	Dysphagia/swallowing, esophagus, stomach ulcers, small intestine ulcers, gastrojejunal ulcers, peptic ulcers, hernia, Crohn's disease, vessel/vascular disorders, diverticulitis, diverticulosis, liver disease, alcohol related liver disease, hepatitis, gallstones, gallbladder disease, pancreatitis
Hormone/Nutrition/Metabolism Diseases	Diseases of the endocrine and metabolic systems and nutritional disorders	Thyroid, diabetes, obesity, failure to thrive, malnutrition, cystic fibrosis, dehydration
Infections	Diseases generally recognized as communicable or transmissible	Sepsis, diarrhea, tuberculosis, Lyme disease, measles, rubella, hepatitis, HIV
Muscle/Bone Diseases	Diseases of the musculoskeletal system and connective tissue	Rheumatoid arthritis, lupus, arthritis, osteoarthritis, osteoporosis
Nervous System Diseases	Diseases of the nervous system	Medication/antipsychotic drug interactions (neuroleptic malignant syndrome), Alzheimer's, Parkinson's, epilepsy/seizures, cerebral palsy, meningitis, multiple sclerosis, mini-stroke, muscular dystrophy
Other	Conditions not elsewhere classified	Multiple organ failure, Raynaud's syndrome, antibiotic resistance
Psychiatric/Emotional Disorders	Disorders of psychological development	Developmental disorder, intellectual disorder, dementia, substance abuse, mood disorders, schizophrenia, personality disorders
Pregnancy/Childbirth/Postpartum Conditions	Conditions during pregnancy, childbirth and the puerperium (post-partum)	Complications of labor and delivery, maternal care related to the fetus and amniotic cavity

Glossary: Category of Death—continued

Category	Definition	Examples
Respiratory Diseases	Diseases of the respiratory system	Hypoxia, asphyxiation, choking, influenza, pneumonia, aspiration pneumonia, viral pneumonia, bacterial pneumonia, bronchitis, emphysema, asthma, bronchiectasis, pneumonitis
Skin Diseases	Diseases of the skin and subcutaneous tissue	Skin infections, dermatitis, eczema
Urinary/Genital Diseases	Diseases of the genitourinary system	Acute kidney disease, chronic kidney disease, renal failure, kidney stones, urinary tract infections, benign prostatic hypertrophy (BPH), other prostate conditions, breast disorders, male genital disorders, female genital disorders, pelvic inflammatory disease, cystitis

Reference: International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization. Retrieved 06/24/15 from <http://apps.who.int/classifications/icd10/browse/2015/en>

Glossary: Funding Sources

Caregiver Supports

A short-term relief period for the primary caregiver, which can be provided in the primary caregiver's home and individual's home or a non-private residential setting. The individual chooses a provider from an approved pick list, who provides the trained staff to supervise and provide assistance with personal care, daily living activities, meal preparation, and medication administration.

Reference: http://www.in.gov/fssa/files/Caregiver_Supports_FAQ.pdf

Community Integration and Habilitation (CIH) Waiver

This waiver provides Medicaid Home and Community-Based Services (HCBS) waiver services to participants in a range of community settings as an alternative to care in a Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities or related conditions. The waiver serves persons with a developmental disability, intellectual disability or autism and who have substantial functional limitations, as defined under the paragraph for "Persons with related conditions" in 42 CFR 435.1010. Participants may choose to live in their own home, family home, or community setting appropriate to their needs. Participants develop an Individualized Support Plan (ISP) using a person centered planning process guided by an Individualized Support Team (IST). The goal of the CIH Waiver is to provide access to meaningful and necessary home and community-based services and supports, seeks to implement services and supports in a manner that respects the participant's personal beliefs and customs, ensures that services are cost-effective, facilitates the participant's involvement in the community where he/she lives and works, facilitates the participant's development of social relationships in his/her home and work communities, and facilitates the participants independent living.

Reference: <http://www.in.gov/fssa/ddrs/2639.htm>

Family Supports Waiver

This waiver provides Medicaid HCBS waiver services to participants in a range of community settings as an alternative to care in a Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities or related conditions. The waiver serves persons with a developmental disability, intellectual disability or autism and who have substantial functional limitations, as defined under "Persons with related conditions" in 42 CFR 435.1010. Participants may choose to live in their own home, family home, or community setting appropriate to their needs. Participants develop an Individualized Support Plan (ISP) using a person centered planning process guided by an Individual Support Team (IST). The IST includes the participant, their case manager and anyone else of the participant's choosing but typically family and/or friends. The participant, with the Team selects services, identifies service providers of their choice and develops a plan of care and is subject to an annual waiver services cap of \$16,545. The FSW provides access to meaningful and necessary home and community-based services and supports, implements services and supports in a manner that respects the participant's personal beliefs and customs, ensures that services are cost-effective, facilitates the participant's involvement in the community where he/she lives and works, facilitates the participant's development of social relationships in his/her home and work communities, and facilitates the participant's independent living.

Reference: <http://www.in.gov/fssa/ddrs/2639.htm>

Glossary: Funding Sources--continued

Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities

This facility is a health facility that provides active treatment for each resident. A facility is only for intellectually and developmentally disabled residents, and is designed to enhance the development of these individuals, to maximize achievement through an interdisciplinary approach based on development principles and to create the least restrictive environment. These facilities are licensed and governed by state and federal regulations and have an annual recertification for Life Safety by the Indiana State Department of Health.

Reference: <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/intermediate-care-facilities-for-individuals-with-intellectual-disabilities-icfid.html>

Nursing Facility

Medicaid-certified nursing homes for individuals who received OBRA services through the Division of Disability and Rehabilitative Services and primarily provide three types of services: skilled nursing, rehabilitation, or long-term care. Nursing facilities are governed by state and federal regulations and monitored by the Indiana State Department of Health. (OBRA stands for Omnibus Budget Reconciliation Act of 1987, a federal law setting forth regulations for Medicare and Medicaid conditions of participation in long-term care facilities.)

Reference: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/nursing-facilities-nf.html>

State-operated Care Facility

State-operated care facilities are institutions providing services to individual with developmental or intellectual disabilities who need long-term and intensive care.

Reference: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/nursing-facilities-nf.html>

Supervised Group Living (SGL or Group Home)

A Group Home or Supervised Group Living (SGL) is a residential option and alternative to waiver placements for eligible individuals with intellectual/developmental disabilities needing services. There are almost 500 Supervised Group Living homes in the State of Indiana with a capacity to serve over 3,000 individuals. Homes are licensed and governed by state and federal regulations and have an annual recertification for Life Safety by the Indiana State Department of Health.

Reference: <http://www.in.gov/fssa/ddrs/2639.htm>